Guide to Developing the Shared Plan of Care

Understanding the Context

National Standards:

According to the Association of Maternal and Child Health Programs (AMCHP), a standard of care for Children and Youth with Special Health Care Needs (CYSHCN) is that they “will receive family-centered, coordinated, ongoing, comprehensive care within a medical home, including care coordination as part of the medical home and integrated with community based services.” (p. 15). “The plan of care... Clearly identifies and delineates the roles, responsibilities, and accountabilities of all entities that participate in a child’s care coordination activities. These entities include but are not limited to physical, oral health and mental health care providers and programs, acute care facilities as needed, and other community organizations providing services and supports to the child and family” (p.16)


Definitions:

Children and Youth with Special Health Care Needs
The federal Maternal and Child Health Bureau defines CYSHCN as “Those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition AND who also require health and related services of a type or amount beyond that required by children generally.”

**Care Coordination**

“Care Coordination” is a process-oriented activity to facilitate ongoing communication and collaboration to meet multiple needs. Care coordination includes facilitating communication between the family, natural supports, community resources, and involved providers and agencies; organizing, facilitating and participating in team meetings; and providing for continuity of care by creating linkages to and managing transitions between levels of care and transitions for young adults in transition to adult services.

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**Medical Neighborhood**

Many of the goals of the medical home (or Patient Centered Primary Care Home – PCPCH) rely on improved communication and coordination among providers outside the walls of the medical home, as well as with the family. This cross-system team is sometimes referred to as the “medical neighborhood.” The “neighborhood” is not necessarily a geographic construct but instead a set of relationships which revolve around the patient and family.


**Shared Plan of Care:**

A shared plan of care (SPoC) is a written document that contains information about a child’s active health problems, medicines they are taking, special considerations that all people caring for the child should know, goals for the child’s health, growth, and development, and steps to take to reach those goals. The SPoC is a tool the medical neighbors and family may use as a team to plan and coordinate care, and to actively work to address gaps, barriers and redundancies in the system of care for children and families. A SPoC promotes cross-system, family-centered care for those children and youth with special health needs who are best served by a team-based approach. Because it lists specific “actions” to be completed, and because team members are mutually accountable to each other, care is coordinated and services are integrated. When a SPoC is implemented, it becomes apparent where the system of care is, or is not, working for the child and family.

A Shared Plan of Care:

- Is responsive to the family and child’s language, culture, needs, and goals.
- Addresses the range of health (physical, oral, behavioral), development, and support needs.
- Is jointly initiated and developed by family, providers, and community professionals.
- Describes family, provider and community professionals’ roles and accountabilities.
- Is used to implement care for the child.
- Is updated regularly.
**Prepare** for the work. **Meet** with your team and **Build** the shared plan of care together.

The SPoC team meets to develop a plan together in real time. Virtual attendance at meetings is allowable, as long as the goal of real-time plan development is realized. This process of coming together allows the team to build a comprehensive picture of a child’s strengths and needs and contributes to a comprehensive action plan.

*Creating a SPoC is a discovery process.* As you work your way through the SPoC template, you may find that you are not immediately able to fill in some of the information asked for. Through discussion, the team will learn more about the child’s medical history, diagnoses, treatments and needs. This information will inform the plan. Filling in the template will likely not be a linear process; the team may need to move back and forth among the sections of the template.

*The success of any care intervention ultimately depends upon actions taken by the patient and family,* so a plan of care must consider the family’s circumstances and capacities. When needs are identified, this information will help drive the shared goals and actions.

*Don’t worry too much about doing everything “exactly right!”* You may need to adapt your process, or make minor changes to the SPoC template in order to meet the needs of your particular team. As the SPoC process is repeated over time with other families, there will be opportunity to improve it. There will be some bugs to work out. Do not let that deter you. In time you will develop a process that works in your community.

**Prepare**

Begin by **identifying a child/family** who will benefit from a SPoC, and inviting them to attend the meeting.

One way to begin is to target children and families who:

- Pose a particular worry or concern to the provider.
- Indicate that they need more help or support.
- Have considerable unmet basic needs or environmental risks.
• Have trouble making, keeping, or getting to appointments.
• Struggle to follow through with agreed upon actions or plans.
• Score highly on any measure of complexity of care needs, or who are identified through the CYSHCN screener developed by the Child and Adolescent Health Measurement Initiative.

Another group who may benefit from a shared plan of care are youth (age 12 or older), especially those who may need additional support in transitioning to adult health care services. Families will require an understanding of the transition process, and the youth will require time to get ready for managing their health care as an adult. For youth older than 12, teams may consider where the youth is in his or her journey toward adult health care and support planning toward transition. Examples of who may benefit from the shared care planning process include:

• Youth who can’t yet explain their medical needs to others
• Youth who can’t yet recognize symptoms, including those indicating a medical emergency, and how to address them.
• Youth who are not yet able to identify an adult care provider, make appointments, and arrange transportation to appointments.
• Families who require support to understand legal changes, including changes in decision-making and privacy and consent.
• Families who require support to understand changes in insurance and access to care.

After this, identify the team (the “neighbors”) who currently support the child/family and invite them to the meeting. Each “neighbor” should bring relevant assessments to the meeting as a basis for developing an effective plan of care. At a minimum, a care planning team should include representatives from:

• The family, of course! The family should be invited by someone who can explain the purpose and the process of a SPoC. If the family needs interpreter services, those should be arranged ahead of the meeting.
• The child’s primary care provider. If the primary care provider cannot attend, they should designate someone (like their care coordinator) to attend on their behalf. A written medical summary should be obtained from the primary care provider.
• The education system. This should include professionals focused on health and development as well as education. For example, you might invite the school nurse, psychologist, and/or special education teacher.
• Mental/behavioral health (if applicable).
• Public health. This might be a CaCoon nurse or another professional who can speak to the family and/or community needs.
Next, determine **how to bring your team together** for a face-to-face meeting, a conference call or some other method of meeting in real time. Think about leveraging other groups who might be meeting to do similar work in your county. For example, is your local CCO convening patient care meetings that you might build on? Are there IEP or other meetings through the school district that could be expanded to include this work?

**Check for Family-Centeredness:** If you plan to use technology to convene the meeting, the family needs to have equal access.

If the family needs an interpreter, make arrangements to have that service available during your team meeting.

**Meet with your Team and Build the Shared Plan of Care Together**

**A Section-by-section Guide to the Template**

Make sure that appropriate **Release of Information** has been signed by each member of the team. It may be helpful to remind everyone of HIPAA requirements at the beginning of the meeting.

Begin by identifying a **process for planning and organizing** the care planning meeting. This will include agreeing on a plan for recording, sharing, and updating the SPoC. The goal is for all the participants to have access to the same information about current goals, activities, and progress.

Identify a **facilitator** who will walk the team through building the plan, as well as a **scribe** who will record the SPoC. The facilitator may be the public health representative who convened the meeting, or the facilitator may be another team member who feels comfortable leading the team through the planning process.

**Demographics:** Fill in this section with the relevant family and child information.
**Check for Family-Centeredness:** Does the team know how to pronounce the child’s and family members’ names correctly? Has the parent had a chance to invite who they want to the team, or to exclude those they do not want on the team? Has enough time been taken to introduce the family to the team?

**Child/Family Strengths and Assets:** The team will identify the strengths and assets of the child and family. Remember that these strengths and assets will be used to advance goals in the plan. Avoid listing descriptors that do not advance goals, such as “he is a cute kid” or “has an engaging smile.” While these may be interesting details that help the team know the child better, in this meeting, it is more helpful to think of strengths as something to build upon. A good example might be: “Joey does not object to taking his medications, and even reminds his parents when it is time to take them.” Or, “Molly carries a purse and is willing to keep her medical information in it.”

**Check for Family Centeredness:** Has the parent had an opportunity to add strengths and assets? If present, has the child or youth had an opportunity to say what they are good at and how they can help with the SPoC?

**Child/Family Language and Culture Needs:** Discuss and record specifics of how your team will address language and culture needs. Cultural elements may include many dimensions, such as spirituality, disability status, sexual orientation, gender identity, and geography, as well as language, race, and ethnicity.

**Check for Family Centeredness:** In addition to language or translation needs, is the team aware of the family’s other cultural practices or beliefs related to health and health care? Has the family had a poor experience in the past with translation? If so, how might it be improved?
Child/Family Concerns and Goals: Record the child and family concerns and goals. Some families may have difficulty expressing goals – not because they have none, but because it is hard to choose just one or two. The team will be asked to record at least one goal that is a priority for the family and this goal becomes a priority for the team. The team will want to agree on whether a goal is a short-term goal or a long-term goal so they can set realistic actions and timelines for achieving them.

Remember that children of almost any age may provide information that is important to building the care plan. For example, if a child has a goal of playing on the playground, there may be specific actions that can help the child achieve his or her goal.

Check for Family Centeredness: Has the SPoC team acknowledged that choosing goals may be difficult for some families? If the family cannot articulate goals, and the SPoC team suggests goals, have the goals been presented in a way the family understands? Is the SPoC team sure that the family agrees with the goals?

Brief Medical Summary: The medical summary is provided by the primary care provider (PCP). It is a concise, up-to-date profile of a child’s condition, status, treatments and needs. It includes current/pertinent and historical medical facts, with interventions tried and not yet tried. The PCP may prefer to provide input securely (such as by a secure e-mail to the team) if he or she cannot attend in person.

Check for Family Centeredness: Does the family agree with the medical summary? Have they had an opportunity to correct any error or add important information? The meeting is an opportunity for the family to provide this input.

Brief Summary of Involvement with Community Services and Education: In this section you will describe the child's experience with various community-based services, including education. The team will consider questions such as: What is the child’s current placement in school? Has he/she been attending school regularly? How well does he/she function there?
What are his or her needs during the school day? What other services has the child used in the past, and what services is she or he presently using?

**Check for Family Centeredness:** Does the family agree with the *summary of community services and education*? Have they had an opportunity to correct any errors or add important information?

**Care Mapping Exercise:** Children and Youth with Special Health Care Needs frequently rely on a large number of services, providers, and resources to ensure care and support. This exercise provides a visual description of a family's *current* needs and supports, and enables the care team to appreciate how each of these aspects relates to the others.

On a large piece of blank paper, work together to draw a map of the current “medical neighborhood” with the family and child at the center. You may also use the mapping template available on the Oregon Family-to-Family Health Information Center website: [http://oregonfamilytofamily.org/tip-sheets.html](http://oregonfamilytofamily.org/tip-sheets.html). (Scroll to “My Child’s Team.”)

Do not use the map, at this time, to identify team members who might be added in the future. The team may choose to do that later, but it is important to focus on current reality before deciding on next steps. The team may choose to make the completed map part of the written care plan, or the document may be discarded after use.

It is not uncommon for many of those who appear on such a map to be unaware of one another. It is an important benefit that community providers learn about one another’s respective roles. This understanding may foster more effective collaboration.

Examples of community providers who may be involved with a child/family include:

- Child care and/or respite care
- Community Connections Network
- Dentist/Orthodontist
- Department of Human Services – Child Welfare and/or Self-sufficiency Programs
- County Developmental Disabilities Program
- Durable medical equipment agency
- Early Intervention/Early Childhood Special Education (EI/ECSE)
- Emergency medical services
- Intensive Case Care Managers at the Coordinated Care Organization (CCO)
• Community-based family support organizations
• Housing programs
• Medical specialists
• Mental health services
• Occupational therapy
• Pharmacy
• Physical therapy
• School systems, including special education and/or the school nurse
• Special Supplemental Nutrition Program for Women, Infants & Children (WIC)
• Speech therapy
• Supplemental Security Income (SSI)
• Transportation supports

**Check for Family Centeredness:** Has the SPoC team considered that it may be difficult for families to name all of the services they receive or, that they may not wish to reveal them? Has the family had the opportunity to tell the SPoC team about community activities they participate in that may be “therapeutic” but not “therapy?” For example, does the family volunteer in the community or visit elderly family members?

**Team Members Contact List:** Based on the map you have drawn, you will list team members and their contact information. You will see that some roles have already been listed. Lines can be added to include team members, or neighbors, as needed. It is possible that not all current team members are able to attend a given meeting. You may want attendees to initial the line with their names for tracking purposes.

**Developing the Action Plan:** The action plan is the blueprint for implementation of the SPoC. It begins with developing goals that are shared by everyone on the team, most importantly the family.

Each team member or agency will have goals specific to their area of expertise. Only some of those goals are pertinent to the shared goals and actions. Team members might find it helpful to first use a separate sheet of paper to write out individual or agency goals before determining and documenting the shared goals. Prioritize the goals and add them to the plan. The family should identify the highest priority goal.
For each goal, list specific actions that will help to achieve that goal. A goal may have any number of actions. Each action should indicate who is responsible along with a timeline. This describes WHO will do WHAT by WHEN.

If the child/youth is aged 12 or older, at least one goal to support transition to adult health care must be included. Consider how the youth will gain skills to manage their condition and their health care. These skills will take time to develop. The table below provides examples of transition goals by age range. The youth’s developmental age is a consideration in how and when goals are written.

<table>
<thead>
<tr>
<th>General Age Ranges</th>
<th>Examples of Transition Goals by Age Range</th>
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<tbody>
<tr>
<td>Ages 12-13</td>
<td>The family/youth will understand the pediatrician’s approach to transition and supports that may be offered to assist in the transition to adult care.</td>
</tr>
<tr>
<td>Ages 14-15</td>
<td>The youth will have a transition plan in place. The youth will know what information to bring to doctor appointments. The youth will know his medicines, what they are for, and when he needs to take them. The youth will be able to track his own health care information.</td>
</tr>
<tr>
<td>Ages 16-17</td>
<td>The family/youth will have a transition plan (or updated transition plan) in place. The family/youth will have an Emergency Care Plan in place. The youth will recognize symptoms, including those of indicating a medical emergency, and how to address them. The family will understand legal changes, including changes in decision-making and privacy and consent. The family/youth will identify an adult provider. The youth will know how to make doctor appointments and arrange transportation.</td>
</tr>
<tr>
<td>Ages 18-21</td>
<td>The young adult will transfer to adult health care with a transfer package of information for the adult care provider or specialist. The young adult (on commercial insurance) will be aware of insurance options after he turns 26.</td>
</tr>
<tr>
<td>Ages 22-26</td>
<td>The young adult will access a new health insurance option(s).</td>
</tr>
</tbody>
</table>
As the plan comes together, consider two important questions:

- Does the plan address the range of health (physical, oral, behavioral), development, and support needs?
- Is the plan responsive to the needs and goals of the child and family, including cultural and language needs?

**Check for Family Centeredness:** Have you moved slowly enough that the family understands who will do what by when? Have you avoided any confusing jargon or acronyms in the plan? Do the parents have the willingness and ability to complete the tasks assigned to them? Is the plan more than a list of tasks for the parent to complete and report on? Does everyone on the team have something to be accountable for? Does the child, if they are able, have a role to play? If so, does the entire team agree about it?

**What does the team do at the end of the meeting?**

- Review the care map you drew earlier and determine whether new “neighbors” need to be added to the team in order to achieve the identified goals.
- Review the plan as a team and make sure the identified actions are practical and feasible. Adjustments to the action plan may be made as needed. The facilitator should verbally summarize the final agreement for clarity.
- Decide what process will be used to determine whether identified actions were completed successfully. One way for this to happen is for each person who took responsibility for an action to report back to a team member who agrees to take on that role. Team members are mutually accountable for the SPoC.
- Identify communication methods that the team intends to use, for example e-mail, phone, or face-to-face communication.
- Decide where the SPoC will “live” and how team members can access it. SPoCs are only valuable to the extent that they are used, so accessibility is important. Will the
document be scanned into an electronic health record (EHR)? If so, who can access that record? Will it be kept as a paper copy?

- Consider how the plan will be updated. The team may choose to schedule another meeting to update the plan.

**Check for Family Centeredness:** Ask the family their understanding of the next steps in their child’s care. Ask whether they were satisfied with the process and what questions they still have.

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**Final Check!**

Make sure the SPoC:

- Is based in and responsive to accurate and appropriate assessments.
- Demonstrates evidence of support to increase patient/family engagement with primary care; specifically a patient centered primary care home when available.
- Demonstrates evidence of effective coordination with the primary care physician and specialty providers, as well as the broader health care team. Coordination includes:
  - Timely and appropriate referral to needed services.
  - Identification and problem-solving around barriers to referral follow-up.
  - Identification and elimination of redundancy of services.
  - Timely, informative, and concise updates that are shared with appropriate members of the health care team, including the primary care provider and the family.
- Demonstrates evidence of patient/family centeredness, including:
  - Strategies to increase the child/family’s capacity to obtain, process, and understand health information to make informed decisions about health care.
  - Evidence of child/family partnership in developing the plan of care.
  - Evidence of interventions that increase the patient/family’s capacity to implement the plan of care, e.g. caregiver support, teaching, and provision of anticipatory guidance.
  - Cultural and linguistic responsiveness.
- Anticipates and supports youth transition to adult health care.
- Is re-evaluated as required with changing circumstances, but no less frequently than every six months.
- Is responsive to the needs and goals of the family and child, including cultural and language needs.
For more information about implementing Shared Plans of Care:


www.lpfch.org/publications/achieving_a_shared_plan_of_care_implementation.pdf
(Search for “Shared Plan of Care” in the search bar.)

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